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## The Effect of a Parental Diagnosis of Cancer on the Occupational Performance of Adolescent and Young Adult Offspring

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# The Effect of a Parental Diagnosis of Cancer on the Occupational Performance of Adolescent and Young Adult Offspring

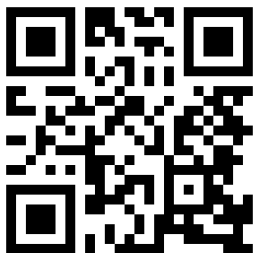
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## Background

There are many supportive services that have been developed to aide cancer patients. However, the cancer patient is not the only one affected. Many of the adolescent and young adult (AYA) children (10-24 years old) of the patient diagnosed become caregivers, providing help with instrumental activities of daily living (IADLs) and providing activities of daily living (ADL) care (Levine et al., 2005). These children may experience intense stress when faced with disruption of family routines and less availability of the parent. There is a gap in occupational therapy literature on the effect of parental cancer on AYA offspring’s occupational performance and performance patterns. During this transitional period of life, parental cancer can potentially damage normal growth and development (Phillips, 2014).

## Purpose

- (a.) To gain an understanding on the current knowledge and practice of OTs relating to the occupational impact that a parental diagnosis of cancer can have on AYA offspring.
- (b.)To determine if there is occupational disruption or imbalance impacting AYAs whose parents have cancer and if OT is a good fit to treat this population.
- (c.) To educate occupational therapy practitioners about the importance of addressing occupations and performance patterns with this population.



References

## Methods

### Scoping review:

- Three stage selection process including eligibility, inclusion/exclusion and duplicate screening and removal.
- 5 electronic databases PubMed, Medline, ProQuest, CINAHL, and ERIC were searched.
- Articles that met the following criteria were included if:
  - (i) they were written in English
  - (ii) focused on adolescent and young adult offspring ages 10-24 years old
  - (iii) one or more parent of adolescent and young adult was diagnosed with cancer
  - (iv) the article mentioned any type of impact on occupations using the OTPF as a guideline (AOTA, 2014). Articles were included if they contained relevant information on OTPF domains.

### Qualitative study:

- Participants must be licensed occupational therapists currently working in oncology or pediatric settings.
- Virtual interviews composed of 10 open-ended questions were recorded and transcribed.
- Transcripts were uploaded onto coding software, Dedoose. After reviewing the data, codes were assigned to the text based off the OTPF.

## ASSESSMENT & TREATMENT



## Results

### Scoping review:

- Most commonly affected...
  - IADLs
  - Social participation

### Qualitative study:

Table 2. Main themes, sub-themes, and relevant excerpts from transcripts

Main themes	Sub-themes	Relevant excerpts from transcripts
Occupational performance	ADLs, IADLs, Education, Work, Play/leisure, Social participation	(P3):"IADLs like cooking, housework, laundry, anything related to cleaning, home maintenance. That may fall on their children and their adolescent and young adult children." (P9): "She started not doing her work. She started coming to school a little disheveled, was very off-task, became very sullen and introverted, and then her grades started suffering."
Performance patterns	Roles, Routines, Rituals	(P6):"My siblings were taking on more caregiving responsibilities. But we were also talking about how they need to be responsible for themselves and then also they may be responsible for other family members or depending on the family situation, the parent who has cancer. It's like balancing two different roles- the role of the kid and then the role of the caregiver." (P9):"Your whole routine is all thrown off because everything revolves around what's going on that day... A lot of children I don't think comprehend what's going on, so behaviors occur when routines are thrown off."
OT scope of practice	N/A	(P6):"Reflecting on my experience and talking about it, I don't know if I can say yes or no. But I definitely found that there is something to work with. It would be a good place for some kind of pilot or group protocol written up."
Assessment & treatment	N/A	(P8):"You could do a family group. That way, treating mom and the family together as a unit instead of separating it with just children or parents."
Barriers	N/A	(P1):"I think that [direct access to this population] would be a barrier. Just finding patients who have children where both the patient and the child are willing to be a part of this group."
Support systems	N/A	(P6):"At that point I would have been more interested in a psychosocial support group, which I guess OT also has a place for that. So that was in my personal experience what I thought was lacking."

## Discussion

- A majority of participants agreed that a parental diagnosis of cancer could affect AYA offspring’s occupational performance and performance patterns.
- Without enough occupational therapy literature on this topic, many of the participants felt like they needed more research conducted on AYA offspring unmet occupational needs before they could definitively say whether OTs should have a role in providing treatment.

Table 1. Scoping review OTPF themes

Author(s)	Journal	Relevant OTPF Terms
Aldridge, J. & Becker, B. (1999).	Journal of Family Therapy	Roles, IADLs, education
Clemmens, D. (2009).	Oncology Nursing Forum	IADLs, social participation, leisure/play, education
Davey, Askew, et al., (2003).	Families, Systems & Health	Roles, routines, IADLs
Davey, Gulish, et al., (2005).	Journal of Marital and Family Therapy	Social participation, IADLs, roles, ADL
Davey, Tubbs, et al., (2011).	Psycho-Oncology Journal	Roles, routines, IADLs, social participation, play/leisure
Davey, Niño, et al. (2012).	Qualitative Health Research	IADLs, routines
Fletcher et al. (2019).	International Journal of Behavioral Medicine	Roles, education, work, IADLs
Gazendam-Donofrio et al. (2007)	Annals of Oncology	Roles
Ghofrani et al. (2019).	Supportive Care in Cancer	Play/leisure, social participation
Gabiak et al.,(2007).	Psycho-Oncology Journal	Education, ADLs, play/leisure, social participation, roles, IADLs
Huang et al., (2014)	Psycho-Oncology Journal	rituals, roles, routines IADLs, social participation, play/leisure, education
Huizinga et al., (2011).	Annals of Oncology	Social participation
Ireland & Pakenham (2010).	Psychology, Health & Medicine	Roles, IADLs
Jeppesen et al., (2014).	Cancer Medicine	Education
Kristjanson et al. (2004).	Oncology Nursing Forum	Social participation
McDonald et al., (2016).	Psycho-Oncology Journal	IADLs, play/leisure, social participation
Morris, Martini, et al., (2016).	Support Care Cancer	Education, social participation, play/leisure, roles, IADLs
Morris, Turnbull, et al., (2018).	Journal of Adolescence	IADLs, roles, education, social participation
Morris, Zajac, et al., (2019).	Australian and New Zealand Journal of Public Health	IADLs, roles, ADLs
Nelson, E. et al. (1994).	Journal of Cancer Education	IADLs, play, play/leisure, social participation, education, routines
Patterson, Pearce, et al., (2011).	Support Care Cancer	IADLs, play/leisure, work, and education
Patterson, McDonald, et al., (2017).	Psycho-Oncology Journal	Social participation, play/leisure, IADLs, education, work
Phillips, F. & Lewis, F. (2015).	Palliative Medicine	Social participation, roles, IADLs
Spira & Kenemore (2000).	Clinical Social Work Journal	Roles
Stiffler et al. (2008).	Oncology Nursing Forum	Roles, IADLs, leisure
Thastum et al. (2008).	Clinical Child Psychology and Psychiatry	IADLs, roles
Varathakeyan et al., (2017).	Support Care Cancer	IADLs, social participation
Walczak et al., (2018).	International Journal of Nursing Studies	Social participation, play/leisure, education, work